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# MENTAL RETARDATION BULLETIN

COMMONWEALTH OF PENNSYLVANIA

DEPARTMENT OF PUBLIC WELFARE

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SUBJECT:

SUPPORTING PEOPLE IN THE COMMUNITY

BY:

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Deputy Secretary for Mental Retardation

## SCOPE:

County Mental Health and Mental Retardation Administrators  
Base Service Unit Directors  
Community Home Directors  
Family Living Home Directors  
Adult Day Care Center Directors  
Vocational Facility Directors  
Intermediate Care Facility for the Mentally Retarded (ICF/MR)  
Directors  
Early Intervention Program Directors  
County Mental Retardation Fiscal Directors  
County Mental Retardation Coordinators

## PURPOSE:

The purpose of this bulletin is to offer principles and suggestions for supporting individuals in the community. Rather than a formula or set of instructions, this bulletin serves as an introduction to our common discovery of community which will be eclipsed by future experiences. This bulletin may also be useful in developing safeguards with individuals who no longer rely on licensing of their living and other community arrangements.

## BACKGROUND:

Community support relies on family, friends, neighbors and community resources to ensure that individuals are able to live as they choose in their community. The roots of community support in Pennsylvania are consistent with the principles which embodied the inception of community living and family resource services in the early 1970's. Today's community support is reflected in programs and initiatives developed by the Office of Mental Retardation's Planning Advisory Committee, as expressed in its publication. Everyday Lives.

COMMENTS AND QUESTIONS REGARDING THIS BULLETIN SHOULD BE DIRECTED TO:

The Community Supports Subcommittee of the Planning Advisory Committee, Office of Mental Retardation, Room 512, Health & Welfare Building, Harrisburg, Pennsylvania 17120

Community support is a way of life which applies principles and values that stress the connection and interdependence between an individual and the individual's community. The principles of community support promote relationships, autonomy and opportunities for meaningful participation in community life. The characteristics of community support are found in various types of licensed and nonlicensed services. Although community support uses both formal and informal service arrangements, community support incorporates resources which extend beyond the control of formalized service networks.

The term community support is sometimes used incorrectly to refer to nonlicensed living arrangements or as a specific model with specific service limits. Community support is not a service model into which people must fit. The principles of supporting people in the community apply equally to all living arrangements whether they are licensed or unlicensed, as well as to services and experiences outside of the individual's home.

#### CHARACTERISTICS OF COMMUNITY SUPPORT:

The following characteristics of community support have been recommended by the Office of Mental Retardation Planning Advisory Committee, Subcommittee on Community Support.

- Community support relies on enduring voluntary relationships between individuals and other persons in their community.
- Community support emphasizes the use of resources which contribute to a person's sense of value as a member of the community.
- Community support relies on the support of the individual's family, friends, neighbors and co-workers.
- Community support engages safeguards that are utilized by the general community which help to ensure an individual's health and well-being.
- Community support changes over time in response to changes in the individual's vision and life conditions.
- The quality of community support cannot be separated from the individual's satisfaction with life in the community.
- Individuals have autonomy around all facets of community life without unnecessary interference from service structures and practice.
- Community support values an individual's culture, traditions, spirituality and religious preference.
- Community support recognizes and celebrates the reciprocal gains which an individual with disabilities offers to the community.

- Community support relies on the choice of individuals to live as part of their communities. This includes the individual's choice:
  - a. in selecting their home, furnishings and decor, other household members, and daily routines.
  - b. in personal association and relationships which offer companionship and intimacy.
  - c. to pursue paths toward occupational and other forms of personal fulfillment.
  - d. to select and dismiss providers of service who do not meet the individual's personal standards.
  - e. to assume responsibility and take reasonable risk for personal decisions.

ROLES OF THE COUNTY PROGRAM AND SERVICE PROVIDERS:

County MH/MR Programs, in concert with service providers, can play an important role in assisting individuals who receive community support. Formalized services can facilitate community support by:

- fostering enduring relationships among people, including friendships not tied to formal services.
- taking direction from the individual in the character of support and services which are offered.
- developing structures which express person centered and community oriented outcomes.
- continuing assistance for individuals to access community support.
- advocating and providing guidance for individuals through troubled times and complex situations.
- educating the community in supporting individuals.
- assisting the individual in maintaining health and well-being.
- developing meaningful leadership opportunities for individuals who receive services, their families, and others outside of formalized service networks.
- reorienting formal systems to be more inclusive of people from various walks of life and with different points of reference.

- offering space, opportunities and encouragement so that community safeguards, relationships, and interdependence can grow and flourish.
- sharing experiences of success and struggle with others who are pursuing community support.
- encouraging use of community resources.

#### HEALTH AND WELL-BEING

Individuals living in the community rely on a variety of methods to ensure individual health and well-being. These methods have generally relied on:

- adherence to a person-centered approach with the individual to ensure that reasonable safeguards are in place to avoid exploitation and harm.
- identification of one best friend, neighbor, family member, service provider or casemanager to be a guide, coordinator, mentor or advocate in aspects of community life.
- the participation of friends, family, neighbors, and co-workers at different places and times.
- ensuring that the individual is aware of and supported in exercising his/her rights.
- familiarizing the individual with the use of precautions appropriate to different situations and conditions.

#### ADDITIONAL RESOURCES:

There are numerous resources available to assist professionals, parents, and community members in applying the principles of community support to practice.

These resources include:

- a growing body of research, reading and reference material, including the attached bibliography from the 1992 publication Supporting People with Severe Reputations in the Community by Michael W. Smull and Susan Burke Harrison. Additional written material is available by writing the Office of Mental Retardation in care of the Community Supports Subcommittee.

- the stories of people in our own communities who are experienced in grass roots community organization and the struggle for the rights, opportunity, and dignity of others.
- technical assistance and training opportunities made available through provider and advocacy associations, local and State agencies. Announcements dealing with technical assistance provided by the Office of Mental Retardation will continue to receive wide distribution.

## **Bibliography and Suggested Readings:**

Allen, W. T., (1989). Read my lips, it's my choice. Free copies available from: Governor's Planning Council on Developmental Disabilities, State Planning Agency, 300 Centennial Office Building, 658 Cedar Street, St. Paul, MN 55155.

Bradley, V. J., & Bersani, H. A. Jr. (1990). Quality assurance for individuals with developmental disabilities it's everybody's business. Baltimore, MD: Paul Brookes.

Condeleluci, A. (1991). Interdependence: the route to community. Orlando, FL: Deutsch.

Edgerton, R. B., & Gaston, M. (1991). I've seen it all. Baltimore, MD: Paul Brookes.

Fisher, R. & Ury, W. (1983). Getting to yes: negotiating agreement without giving in. New York: Penguin Books.

Fullwood, D. (1990). Chances and choices. Baltimore, MD: Paul Brookes.

Green-McGowen, K. (1985). Functional life planning. Peachtree City, Georgia: K M G Seminars.

Lovett, H. (1985). Cognitive counseling and persons with special needs. New York: Praeger.

Lovett, H. (1991). Empowerment and Choices. In Meyer, L. H., Peck, C. A., & Brown, L. Critical issues in the lives of people with severe disabilities. Baltimore, MD: Paul Brookes.

McGee, J. J. (1989). Being with others: Toward a psychology of interdependence. Omaha, NE: Creighton University Press.

Mount, B. (1991). Dare to dream: An analysis of the conditions leading to personal change for people with disabilities. Available from: Communitas, Inc. P.O. Box 374 Manchester, CT 06040.

Mount, B. (1990). Imperfect change, embracing the tensions of person-centered work. Available from: Communitas, Inc. P.O. Box 374 Manchester, CT 06040.

Mount, B. & Zwernik, K. (1988). It's never too early, it's never too late. St. Paul, MN: Metropolitan Council. Publication No. 421-88-109.

National Association of Private Residential Resources (Eds.) Supported living: Monograph (1991) and Supported living: Monograph Volume II (1992). National Association of Private Residential Resources, Annandale, VA.

## Bibliography

O'Brien, J. (1990). A survey of emerging issues in supported employment for people with severe disabilities. Report available from: Responsive Systems Associates, 58 Willowick Drive, Lithonia, GA 30038-1722.

O'Brien, J. (1987). A guide to life-style planning. In B. Wilcox & T. G. Bellamy (Eds.), A comprehensive guide to the activities catalog an alternative curriculum for youth and adults with severe disabilities. Baltimore, MD: Paul Brookes.

O'Brien, J. & OBrien-Lyle, C. (1991). More than just a new address. Report available from: Responsive Systems Associates, 58 Willowick Drive, Lithonia, GA. 30038-1722.

O'Brien, J. & CBrien-Lyle, C. (1992). Remembering the soul of our work. Madison, WI: Options in community living.

O'Brien, J. and Mount, B. (1991) Telling new stories: The search for capacity among people with severe handicaps. In Meyer, L. H., Peck, C. A., & Brown, L. Critical issues in the lives of people with severe disabilities. Baltimore, MD: Paul Brookes.

Perske, R. & Perske, M. (1988). Circles of friends. Nashville, TN: Abingdon Press.

Pearpoint, J. (1991). From behind the piano: The building of Judith Snow's unique circle of friends. Ontario, Canada: Inclusion Press.

The power to choose (1990). Ontario: The G. Allan Roeher Institute.

Racino, J. A. (1990). Preparing personnel to work in community support services. In A. P. Kaiser & C. M. McWhorter (Eds.), Preparing personnel to work with persons with severe disabilities. Baltimore, MD: Paul Brookes.

Sher, B. (1979). Wishcraft: How to get what you really want. New York: Ballantine Books.

Smith, G. A. (1990). Supported Living: New Directions in Services to People with Developmental Disabilities. (Community Management Initiative Series). Alexandria, V A: NASMRPD.

Smull, Michael W. "Crisis in the Community". University of Maryland at Baltimore, School of Medicine, Department of Pediatrics, 1990.

Smull, Michael W. "Escaping the Label Trap". Published in the News and Notes of the American Association on Mental Retardation. Sept/Oct. 1991, Vol.4, No.5.

Smull, M. W. & Bellamy, T. G. (1991) Community services for adults with disabilities: Policy changes in the emerging paradigm. In Meyer, L. H., Peck, C. A., & Brown, L. Critical issues in the lives of people with severe disabilities. Baltimore, MD: Paul Brookes.

Sutherland, A. T. (1991). Disabled we stand. Bloomington, Indiana: Indiana University Press, Bloomington, Indiana.

Taylor, S. J., Biklen, D. & Knoll, J. (1987). Community integration for people with severe disabilities. Columbia University: Teacher's College Press.

Taylor, S. J. & Racino, J. A. (1991). Community living: Lessons for today. In Meyer, L. H., Peck, C. A., & Brown, L. Critical issues in the lives of people with severe disabilities. Baltimore, MD: Paul Brookes.

University Affiliated Program of New Jersey (Eds.) (1991). Middle Management Training: Part One - Vision and Ideals and Middle Management Training: Part Two - Implementation. Available from the University of Medicine and Dentistry of New Jersey, 675 Hoes Lane, Piscataway, NJ 08854-5635.

Vandercook, T., York, J., & Forest, M. (1989). The McGill Action Planning System (MAPS): A strategy for building the vision. JASH. 14,205-215.

Wetherow, D. (1990). An Introduction to the Whole Community Catalog. Available from: Communitas, Inc.

Wieck, C. & Strully, J. L. (1991). What's wrong with the continuum? A metaphorical analysis. In Meyer, L. H., Peck, C. A., & Brown, L. Critical issues in the lives of people with severe disabilities. Baltimore, MD: Paul Brookes.

Williams, P. & Shoultz, B. (1982). We can speak for ourselves. Bloomington, IN: Indiana University Press.

From: SUPPORTING PEOPLE WITH SEVERE REPUTATIONS IN THE COMMUNITY by Michael W. Smull and Susan Burke Harrison, September, 1992

Price: \$10.00 per copy. Copies may be ordered by contacting:  
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